The Collaborative Chronic Care Network (C3N) aims to demonstrate a new approach for chronic illness care. Patients, clinicians, and researchers collaborate to learn from every interaction; they conduct research and implement the findings. C3N combines large clinical data registries with patient-entered data and makes them accessible and interactive. C3N is a platform for researchers to design, test, and implement new knowledge and innovations in patient care. To test the platform, C3N is working on a model of treating children with inflammatory bowel disease (IBD) using the ImproveCareNow Network of pediatric clinics.

Mission

C3N is based on the premise that collaboration between patients, their families, clinicians, technology developers, and researchers will improve patient outcomes in and outside of a clinical setting.

- 2004: A group of physicians from eight medical institutions began a “research and improvement network” with funding from the American Board of Pediatrics. Initially, this group focused on studying variations in the care of children and teens afflicted with Crohn’s disease.
2007: The PIBDNet Trailblazer Improvement Collaborative launched with funding from participating institutions in addition to federal grants and charitable contributions. The collaborative’s goal was to demonstrate that an active, open, learning health network that uses collaboration and data sharing can drive improvements in the care and health of all children with Crohn’s disease and ulcerative colitis.

2009: The collaborative changed its name to ImproveCareNow, a network of 46 centers focused on quality, improvement, and research in the care of pediatric IBD.

2010: C3N was launched, based on the COIN (Collaborative Innovation Network) framework, a collaborative environment focused on maximizing interactions between participants and leadership across different participation levels. C3N applies this framework to the clinical setting, so that health care and treatment decisions are guided by a continuous learning network of patient data and provider practices.

2010: The U.S. Agency for Healthcare Research and Quality (AHRQ) awarded $12 million to Cincinnati Children’s Hospital to build the data and informatics infrastructure for the C3N data network.

2011: Cincinnati Children’s Hospital awarded $200,000 to C3N to further develop the C3N personalized learning system.

2013: AHRQ awarded $750,000 to Cincinnati Children’s to enhance the sustainability of the C3N system.

With the support of C3N, the ImproveCareNow Network has grown to more than 58 sites that provide care for 17,000 patients in 31 states—about one-third of all children with IBD in the United States.

C3N has the following:

- A diverse team of experts from medicine, public health, psychology, computer science, film, design, law, sociology, communications, and economics

- An innovation network of more than 100 patients, parents, clinicians, and researchers—all
contributing actively to C3N as co-designers

- Fifty-eight IBD care centers with 49 gastroenterologists and 17,000 IBD patients
- A nascent innovation network of 25 patients, parents, clinicians, and researchers—all contributing actively to the design of a C3N for cystic fibrosis
- Tested prototypes of 20 innovations

**Structure & Governance**

C3N is managed by two principal investigators and six staff members. It is housed at the James M. Anderson Center for Health Systems Excellence at Cincinnati Children’s Hospital Medical Center. The C3N strategy is informed by parent and patient working groups. Forty patients and parents representing the children and families are in ImproveCareNow, all of them living with Crohn’s disease and ulcerative colitis. These working groups provide insight to research studies, contribute to the development of C3N innovations, and learn from interactions with clinicians, researchers, and other health professionals. Social media–based technologies also play a large role in C3N’s efforts.

**Financing**

C3N has multiple sources of funding, particularly from federal agencies. It is funded through an $8 million transformative R01 (TR01) grant from the National Institutes of Health. AHRQ has awarded two grants: the first is a $12 million grant to build the data and informatics infrastructure for the C3N data network, and the second is a $750,000 grant to enhance the sustainability of the data and technology system. In addition, C3N receives funding from donors, fees from participating centers, and other small grants.

**Intellectual Property**

The C3N learning health system aims to make it easier, faster, cheaper, and better for patients,
families, clinicians, and researchers to drive improvement, discovery, and innovation.

Software code is not typically patentable, and the C3N informatics infrastructure is built on the open-source i2b2 infrastructure; therefore, there are no formal intellectual property (IP) protections around the informatics infrastructure. Likewise, no IP is associated with the data housed within the database.

C3N’s commercializable IP are the tools, processes, methods, and general know-how necessary to build a successful network. C3N investigators and staff have developed the expert knowledge required to replicate the network model, and this transferable know-how confers economic value to the methodology.

**Patent Engagement**

C3N views patients as co-designers in the development of a learning health care system, and efforts have been taken to include patients in every aspect of the C3N model. For example, C3N’s design partner Lybba conducted extensive ethnographic research to create sets of user personas, each of which is an archetype representing the needs and goals of a particular user group. Throughout the design and development process, the personas consistently embody key user motives and actions that inform product creation.

Patients also participate in the C3N project through the following:

- **The E3 Healthcare Study** (Engaged, Empowered, Electronic) uses automated tools to optimize clinical interactions and shared decision-making. The tools provide patients and parents with the right information at the right time — helping them understand the information and teaching them how to use it with their healthcare team.

- **Emma App**, an iPad app, is designed to engage young patients in the waiting room while giving clinicians a quick pre-visit snapshot of their condition. Emma aims to test and increase patient knowledge in four areas: quality of life, wellness, patient nutrition, and general nutrition. The app also aims to change the clinician’s interactions.

- **IBD Volunteers** is a community of IBD patient navigators.
• The Patient Advisory Council (PAC) is referenced above in the governance section.

• Self Management Support is a series of tools aimed at enhancing patient education, motivating patients to ask questions, and improving communication with healthcare providers.

• YouMeIBD is a Facebook app that connects people with IBD based not only on their common diagnosis, but also their shared personal interests. The purpose is to understand how increased social network connectivity among people within a chronic illness population will affect their health outcomes.

C3N enables ongoing measurement of the real-world efficacy of medications, devices, and processes to optimize medication and device use. It provides data for comparative effectiveness research and post-marketing surveillance and tools to facilitate study design, population identification, and recruitment through Informatics for Integrating Biology & the Bedside (i2b2). It engages physicians and patients to inform study design and fosters prioritization through focus groups, surveys, etc. Networks based on the C3N model provide a “lab” to test innovations in care delivery, including information technology.

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Data Sharing

Designed by C3N, the ImproveCareNow Network’s approach to data sharing is based on a learning health system framework that shares performance data in a transparent manner among participating clinical care sites. The registry captures data directly from the electronic health record (EHR) and repurposes the data to support chronic care management processes and population management,
which in turn support quality improvement and comparative effectiveness research.

Data elements are coded to a standard terminology to aid re-use and analysis across projects in real time. Because C3N is designed as a learning tool to identify and decrease variability, the level of sharing is important and is counted toward performance assessment. The analyzed data are integrated into reports that become part of the EHR and clinical workflow.

Data is used for the following:

- To support comparative effectiveness research for populations
- To evaluate and improve care delivery processes at the care center level
- To provide a means for individual “n-of-1” trials and other methods to select the best treatment of individual patient circumstances

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